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# Predictors of Reduced Health-Related Quality of Life in Adult Patients with Idiopathic Inflammatory Myopathies

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## Abstract

**Objective—**Extensive studies on health-related quality of life (HRQOL) in idiopathic inflammatory myopathies (IIM) are lacking. Our objective was to document HRQOL and to identify factors associated with a reduced HRQOL in IIM patients.

**Methods—**A total of 1,715 patients (median age 49.9, 70% female, 87% Caucasian) who met probable or definite Bohan and Peter or Griggs criteria for myositis were included from the MYOVISION registry. HRQOL was ascertained via the SF-12v2® Health Survey questionnaire. HRQOL physical and mental summary scores (PCS and MCS, respectively) in relation to different patient and disease characteristics were compared to scores from the matched normative data from the U.S. general population and rheumatoid arthritis (RA) patients. Bivariate and multiple linear regression analyses were performed to assess the association between HRQOL and patient and disease parameters.

**Results—**The mean summary scores of the SF-12v2® were significantly lower in IIM as compared to the normative and RA populations. A diagnosis of inclusion body myositis, older age, patient-reported negative effect of disease on work, presence of another concurrent autoimmune disease, polypharmacy, and IIM-associated lung disease and joint involvement were all significantly associated with lower PCS scores. Lower MCS scores were associated with joint involvement and a negative effect on work.

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**Conclusion—**In this large study of patient-reported outcomes in IIM, an association was found between multiple disease characteristics and reduced HRQOL, mostly in the physical domain. In the United States, HRQOL in IIM patients was lower compared to the general population and to RA patients.

## INTRODUCTION

The idiopathic inflammatory myopathies (IIM), including dermatomyositis (DM), polymyositis (PM) and inclusion body myositis (IBM), are chronic systemic inflammatory conditions that can involve almost any organ system, but primarily affect muscle (1). Although the prognosis for IIM has improved significantly in the past few decades with advances in medications and health care (2, 3), IIM still carry a significant impact on patients' health-related quality of life (HRQOL) (3–6). HRQOL is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning and is focused on the impact health status has on quality of life (7).

Extensive research has been conducted on HRQOL in other rheumatic diseases such as rheumatoid arthritis (RA) (8, 9), juvenile idiopathic arthritis (JIA) (10,11) and systemic lupus erythematosus (SLE) (12). However, there are few sizable studies assessing HRQOL among patients with IIM (4–6, 13–15, 16). Due to the rarity of these conditions, previous studies had small sample sizes thereby prohibiting adequately-powered statistical comparisons to delineate patient or IIM factors associated with HRQOL outcomes (16, 17).

The Myositis Association (TMA) is an organization that provides support to myositis patients and their families, and the TMA database now includes over 10,000 IIM patients. The National Myositis Registry (called MYOVISION), that has been operated by TMA, provides a wide range of self-reported information about both adult and pediatric patients with IIM, including demographics, clinical manifestations, medications and environmental exposures that may be associated with these diseases. This patient registry also collected information on HRQOL at the time of enrollment.

Using the MYOVISION registry, we attempted to document the degree of HRQOL impairment in adult IIM patients, comparing this to RA patients and to a normal healthy population. Further, we wished to identify predictors of outcomes associated with lower than expected HRQOL among the major IIM clinical groups.

## PATIENTS and METHODS

### MYOVISION Registry participants and survey procedures

This exploratory, cross-sectional study evaluated patients who enrolled in the MYOVISION registry. MYOVISION enrollment packages were mailed between December 2010 and July 2012 to 9,049 patients registered in TMA's mailing list in the United States (U.S.) and Canada. Additional myositis patients could also enroll by responding to study advertisements to receive a mailing or by accessing the TMA website to request participation. Enrollment packages contained a patient questionnaire, as well as the study consent form and a return postage-paid envelope. Potential participants were given the

option to complete the paper version of the questionnaire or an online electronic version. Patient data were not entered into the database until a signed consent form was received. Only patients who met probable or definite Bohan and Peter criteria (18, 19) for dermatomyositis or polymyositis, or possible or probable criteria for inclusion body myositis (20), based on questionnaire data, were included in the MYOVISION registry database. The diagnosis was also ascertained via a partial sample of the patient population seen the National Institutes of Health. The diagnosis reported in the questionnaire was compared to the diagnosis in their NIH medical or research record.

The MYOVISION questionnaire included 83 questions that encompassed patient demographics, disease-related information, environmental exposures, and questions regarding work, school, and leisure activities, as well as HRQOL. Patients were not reimbursed for their participation in the study. For missing data or inconsistent responses to the MYOVISION questions, respondents were re-contacted by phone, e-mail and mail. These quality assurance procedures were conducted by personnel from The Myositis Association and the National Institute of Environmental Health Sciences. Cincinnati Children's Hospital Medical Center's institutional review board served as the IRB of Record that approved the study.

### HRQOL assessment tool

Patients 18 years or older at the time of the questionnaire completion also received the Short Form-12 version 2 (SF-12v2®) HRQOL instrument. The SF-12v2® has been shown to have similar performance characteristics as the SF-36 and was used because of its ease of completion compared to other HRQOL scales (21–23). The SF-12v2® questionnaire is an abbreviated version of the SF-36 questionnaire and is a short 4-week recall questionnaire addressing 12 different items that yield eight different domains (physical functioning [PF], role-physical [RP], bodily pain [BP], general health [GH], vitality [VT], social functioning [SF], role-emotional [RE], and mental health [MH]). Four domain scores (PF, RP, RE, and MH) are based on responses to two items each, whereas the remaining domains (BP, GH, VT, and SF) are represented by a single item. Two summary measures can be derived from the SF-12v2® - the physical component summary [PCS] and the mental component summary [MCS]. The SF-12v2® allows for complete scoring of summary measures even when select item responses are missing, provided at least one item in a two-item domain is answered.

The different health domains and summary scores are presented as normalized T scores with a mean of 50 and a standard deviation (SD) of 10 (24). The means and SDs used when scoring originate from the 1998 U.S. general population norms, derived from responses to the National Survey of Functional Health Status. The factor score coefficients come from the 1990 U.S. general population norms (24).

HRQOL data of age- and gender-matched U.S. normative population and RA patients were derived from a national probability sample of U.S. non-institutionalized adults who participated in the internet-based 2009 QualityMetric PRO Norming Study (23). A total of 8719 individuals participated in this study and 6012 of these individuals received items from the standard version of the SF-12v2. As part of the survey, all respondents were asked "Have

you ever been told by a doctor or other health professional that you had any of the following conditions?" accompanied by a list of over 40 common health conditions, which included RA. Of the 6012 patients who received a survey including the SF-12v2, 463 answered "yes" for RA (24).

## HRQOL Predictors of Interest

We identified *a priori* a series of demographic and clinical variables that we hypothesized to be associated with differences in HRQOL in IIM. The variables included were: (1) gender, (2) race, (3) age at diagnosis, (4) age at enrollment in MYOVISION, (5) duration of disease, (6) IIM effects on work and school, (7) presence of other concurrent autoimmune diseases or cancer, (8) type of treating physician (rheumatologist vs. non-rheumatologist), (9) number of medications used for the treatment of IIM (more than one immune modulator medication vs. one or no medications), (10) associated pulmonary disease, (11) joint swelling, (12) dysphagia and (13) geographic location of residence. The patient's addresses were geocoded using ArcGIS, 10.1. The assigned latitudes and longitudes associated with the patients' addresses at the time of enrollment were used to assign them into four U.S. census regions at the time of enrollment.

## Statistical analysis

Analyses were performed on all adult MYOVISION registry patients as well as the different myositis clinical groups - dermatomyositis (DM), polymyositis (PM), and inclusion body myositis (IBM). The juvenile dermatomyositis (JDM) group had an insufficient sample size and was not included. Descriptive statistics (median, interquartile range and frequency) of the demographic data of the MYOVISION registry population were performed. Using Analysis of Variance statistics, we compared the SF-12v2® domain scores and the two summary measure scores (PCS, MCS) from registrants with IIM to the healthy and RA data.

Bivariate analysis was conducted via t-tests to assess the difference in mean PCS and MCS scores for each independent variable noted above. One-way ANOVA was used to compare the PCS and MCS scores across the four census regions.

Multiple linear regression analyses were used to identify significant HRQOL predictors in the entire IIM population and in the DM, PM and IBM groups. All 13 predictors of interest were included in the multivariate analyses, even if they were found to be non-significant in the bivariate analysis. Both forward selection and backward elimination methods were used to fit an appropriate model for predicting PCS or MCS scores. The significance threshold for keeping a variable in the model was set *a-priori* at p=0.1, except for candidate predictors previously identified to be relevant based on the bivariate analysis. Notably, relevant predictors were identified irrespective of predictor selection approach (backward or forward selection).

Adjusted least squared means and standard errors (SE) of PCS and MCS by IIM group were generated using Generalized Linear Models (GLM). Covariates included were the same as those in the multiple linear regression analyses described above. As this was an exploratory study, p values were not adjusted for multiple tests of hypotheses. Univariate analyses were

performed using GraphPad Prism 6 software, and SAS (SAS, Inc., Version 9.3, Cary, NC) was used for conducting ANOVA and multivariate analyses.

## RESULTS

### Demographic data

A total of 1956 patients (22% of the 9049 to which packets were mailed) consented to participate in the study and returned completed questionnaires (Figure 1). Of these, 1806 patients met IIM diagnostic criteria. HRQOL information (SF-12v2® questionnaire answers) was available for 1648 adult patients, of whom 702 had DM, 481 had PM, and 465 had IBM. There were 67 adult patients with juvenile-onset of disease (juvenile dermatomyositis or juvenile polymyositis) who were not included in this study.

The median age of diagnosis among all patients (n=1806) was 49.9 years [interquartile range 37.3 and 59.6]. As expected, IBM patients were significantly older (62.3 years, [55.5 and 68.2]) at the time of diagnosis than DM and PM (46.4, 47.8 respectively, each P<0.0001). There were 1262 female patients (70%), with a greater female predominance in DM (84%), but a larger male predominance (60%) in IBM (P<0.0001). The vast majority of participants were Caucasian (87% in the total patient group; 93.6% in the IBM group). African-Americans comprised 6% of the total and 12% of the PM group. Disease duration at time of enrollment was 9.2 years for the total patient group [interquartile range 5.3–13.6] without a significant statistical difference among the IIM patient groups.

To assess the accuracy of the self-reported diagnosis, we assessed 121 patients of the total 1806 patients (6.7%) who were patients at the NIH. Among these, in 105 cases (87%), the patient's reported diagnoses matched the NIH physician's diagnoses.

### Comparison of HRQOL scores in IIM compared to the general and RA populations

As shown in Table 1, IIM negatively impacted all health domains captured by the SF-12v2® questionnaire in comparison to the general population, with the most profound negative effect (based on effect size [ES]) on the *physical functioning* (PF) (ES = −1.01) and *role physical* (ES= −0.91) domain. With respect to overall physical function and mental health, both PCS and MCS were significantly lower among those with IIM compared to the healthy U.S. population sample. When compared to RA patients, all domain scores (apart from bodily pain) and both summary scores were significantly lower in IIM patients (Table 2).

### HRQOL scores among IIM groups

PCS scores differed significantly among different IIM groups with IBM showing the most profound impact on overall physical function (IBM mean 30 vs. PM 34.7 vs. DM 39). Conversely, MCS scores did not significantly differ among IIM subtypes (46.6, 46.7, 47.7 respectively).

### Differences in HRQOL based on patient demographics and clinical parameters

In the bivariate analysis of the study population (n=1648), non-Caucasian patients had significantly worse mean PCS (33.6 [SD= 10.2] vs. 35.7 [10.9], P <0.0001) and MCS (44.9

[11.6] vs. 47.5 [10.9], P=0.003) compared to Caucasians. The PCS scores were significantly lower for older patients at diagnosis (median >50) (33.9 [9.5] vs. 37.2 [11.8], P<0.0001) and for older patients at enrollment (median >60) (33.5 [9.5] vs. 37.5 [11.7]) P<0.0001), but the MCS for older patients at diagnosis (47.7 [10.9] vs. 46.8 [11.1] P=0.096) and at enrollment (48.0 [11.0] vs. 46.4 [10.8] P=0.002) were higher. Disease duration did not significantly change the PCS among all patient groups, but MCS was better in DM patients with a longer than median disease duration (45.8 [10.8] vs. 48.5 [10.3], P=0.0007).

Both the PCS and MCS were lower among patients who reported an effect of their disease on ability to work compared to the total patient group (33.7 [10.0] vs. 40.7 [11.3], P<0.0001 and 46.3 [11.1] vs. 50.4 [9.9], P<0.0001, respectively). The PCS was significantly lower among patients with associated autoimmune disease in the DM group (36.0 [11.3] vs. 40.0 [11.6], P<0.0001). However, patients with associated cancer had a better mental score than the total patient group (46.9 [11.1] vs. 48.6 [10.5], P=0.017). When the treating physician was a rheumatologist, PCS was significantly higher in the total patient group (37.1 [11.5] vs. 33.0 [9.3], P<0.00001), but physical score was lower in IBM patients when the treating physician was a rheumatologist (29.3 [6.9] vs. 30.8 [6.6], P=0.044).

Both the PCS and MCS were significantly lower in patients who reported more systemic disease involvement, such as having a history of lung disease (PCS: 32.2 [9.6] vs. 36.8 [11.1], P<0.0001; MCS: 45.6 [11.5] vs. 47.8 [10.8], P=0.0003), swallowing difficulty (PCS: 34.4 [10.4] vs. 37 [11.3], P<0.0001), or joint swelling (PCS: 34.1 [10.3] vs. 36.3 [11.1] P<0.0001; MCS: 45.3 [10.9] vs. 48.4 [10.9], P<0.0001). Region of residence did not significantly impact the PCS or MCS when the entire study population was considered in the analysis.

## Multivariate analyses

In the multivariate analyses of the total IIM patient group (Table 3), older age at enrollment, patient report of a negative effect of disease on work performance, associated autoimmune disease, lung disease and presence of joint disease, as well as use of multiple medications, were all associated with significantly lower PCS scores. Notably, care of an IIM patient by a rheumatologist was associated with a higher PCS. The MCS was negatively influenced by a history of arthritis and a negative effect on work.

Patients with a diagnosis of cancer had a higher MCS and there was a tendency for a higher MCS among patients with longer disease duration. As can be seen in Table 4, these results were quite consistent in the IIM group multivariate analysis. A reported effect on work and a history of arthritis were the most constant parameters with a negative effect on both PCS and MCS in all three IIM groups. In the IBM group, fewer parameters influenced the PCS and MCS scores, as compared with DM and PM. Treatment by a rheumatologist negatively influenced both the PCS and MCS scores in the IBM group. Geographic regions did not significantly influence the MCS or PCS scores in the multivariate analysis (data not shown).

## DISCUSSION

Results from this large registry study in adult patients with IIM showed that overall HRQOL is reduced when compared to either a healthy population or to RA patients. The current study also identified an association among multiple variables and a reduced HRQOL, most of which are in the physical domain. These included older age, effect of disease on work, the presence of another autoimmune disease, lung disease, joint involvement and use of multiple medications.

The reduction of HRQOL, as shown in the current study, is consistent with various other smaller studies that compared IIM patients to the general population (4, 13, 14), as well as analyses assessing all studies in aggregate (16). Other studies have shown comparable reduced HRQOL scores in other rheumatic diseases, including SLE, RA and Sjogren's syndrome (16, 25–28).

A well-recognized, reliable set of demographic, disease, environmental or time-related predictors of HRQOL in IIM has yet to be identified. Our findings relating to predictors of HRQOL in IIM are consistent with a number of earlier studies in some respects, but do vary from others. Somewhat surprisingly, for example, disease duration was not associated with a reduced HRQOL in this and some earlier studies (4, 29), while other authors have found a rather strong association between the two (14, 30). This may be due to variations in study design, sample size or instruments used to assess HRQOL, or in the underlying clinical and therapeutic heterogeneity of the IIM groups themselves.

Rheumatic diseases are well-known to be one of the most common chronic conditions limiting a person's ability to remain in paid employment (31, 32), perhaps due to associated fatigue, pain and emotional and interpersonal issues (33). Indeed, the most significant independent predictor of lower physical and mental aspects of HRQOL in the current study was a patient-reported negative effect of their disease on their ability to work. Ponyi et al. (14) reported that 42% of patients with IIM were unable to work at some point in life due to their disease and that 70% were mildly to moderately disabled despite inactive disease. The inability to remain gainfully employed due to IIM likely contributes to a further reduction in HRQOL. The authors suggest this finding might be partially explained by the increased use of glucocorticoid medications and their secondary side effects such as osteoporosis.

MCS was actually higher in patients with longer disease duration, in older patients and in patients with associated cancer. This apparent discrepancy has been reported in other studies of IBM (6) and IIM (4). This observation might be ascribed to the "disability paradox" (34) and refers to the phenomenon where patients with chronic disease report unexpectedly high levels of HRQOL, perhaps due to resetting of internal expectations through a process of disease assimilation, termed "response shift" (35, 36) or to improved coping strategies. Health care providers and significant others are known to underestimate patient's QOL in comparison to the patients' own evaluation (37). It is worth mentioning that few studies to date have evaluated the disability paradox and response shift in rheumatic or inflammatory diseases.

IBM patients had the most profoundly reduced physical function among IIM patients. Although this finding was not consistently reported previously (4, 6, 13, 14), it is not surprising. IBM has a different demographic profile with an older age of onset (usually over 50 years of age) and larger male predominance (2:1 male: female ratio) (37). Furthermore, there is a concern that IBM may have a degenerative component (39) and it is known to be associated with greater long-term disability, including progressive weakness resulting in significant walking difficulties and wheelchair use (40). IBM is typically treated by neurologists rather than rheumatologists, and is very resistant to treatment (39). Interestingly, treatment by a rheumatologist negatively impacted HRQOL scores in this subgroup, and this may be consistent with a large natural history study that suggests that certain treatments with immunosuppressive agents may modestly exacerbate progression of disability of IBM (40). These differences may explain why HRQOL was lower among IBM patients in comparison to the other groups.

A major strength of this study is the large sample size, enabled by the use of the MYOVISION patient registry. Use of the registry underlies what also may be the study's major weakness. Conducting large, statistically valid studies of health outcomes in rare diseases is extremely challenging and often must rely on non-verifiable patient-reported data. A number of steps were taken, however, in an attempt to address this issue. We attempted to assure the accuracy and completeness of the data, including clarification of answers to questions in which interpretation of the response was unclear or missing, by re-contacting patients to verify their responses or complete missing data, and by including range and acceptable-value checks in the data-entry software.

In recent years registries have facilitated an increase in the scope of research regarding IIM and have permitted some of the first detailed phenotypic descriptions of the IIM groups as well as their individual clinical and serologic classifications (40).

One limitation of this study might be the use of the SF-12v2® rather than the SF-36 for the assessment of HRQOL. The SF-36 is the recommended HRQOL assessment tool and patient-reported outcome measure for the evaluation of response to therapy in myositis by The International Myositis Assessment and Clinical Studies Group (IMACS) (17, 42). Indeed, the SF-12v2® has only been used in a few studies of HRQOL in IIM (6, 13, 15), thereby making comparisons of results from this study to others more difficult. Also, the SF-12v2® does not directly address fatigue as a component of HRQOL, which is regarded today as a foremost component of HRQOL in both RA (43) and adult-onset and childhood SLE (44, 45). Nonetheless, the SF-12v2® is easier and quicker to complete in comparison to the SF-36 and has been shown to have similar performance characteristics (19, 20).

Another limitation, inherent in the use of patient-reported-outcomes, as performed in this study, is the propensity for bias, specifically survivor and participation bias. Only 22% of the patients who received the questionnaire packets responded to the survey. We know that only surviving patients and patients well enough to complete the questionnaire took part in this study, thereby perhaps reflecting a group of patients with less morbidity. However, this consideration might make the results of this study even more compelling. Also, as this is a cross-sectional descriptive study, one cannot deduce cause and effect. As such, for example,

the negative reported effect on work could be both the cause and the consequence of poor health status.

We should also note that we have little data regarding the comparison populations used in this study. For example, respondents reported a diagnosis of RA in the RA population, but we do not have any further information regarding the severity of their disease or its treatment.

In summary, we report a profound reduction, especially in physical function, among IIM patients compared to RA patients and to the general U.S. population. A history of lung and joint involvement, treatment-resistant disease, and the diagnosis of IBM are the most relevant disease-specific risk factors for poor HRQOL in IIM identified in this study.

Further adequately powered studies are needed to assess the strength of the potential relationships between HRQOL and demographic, disease, clinical and environmental characteristics among IIM patients. Conflicting results from earlier studies are likely attributable to the small sample sizes used and heterogeneity among the IIM groups. Additionally, little information is known regarding the patterns of change of HRQOL in IIM patients after therapy and over time. Existing and future patient registries may provide the most feasible method for carrying out such studies.

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### Significance and innovations

- This large registry study demonstrates that the idiopathic inflammatory myopathies (IIM) have a more profound negative impact on HRQOL as compared to rheumatoid arthritis and the general US population as measured by the SF-12v2®.
- This study identifies multiple disease parameters associated with a reduced physical component of HRQOL in IIM.
- Similar to HRQOL studies in other rheumatologic diseases, this study shows little influence of demographic or disease parameters on the mental component of HRQOL in IIM.

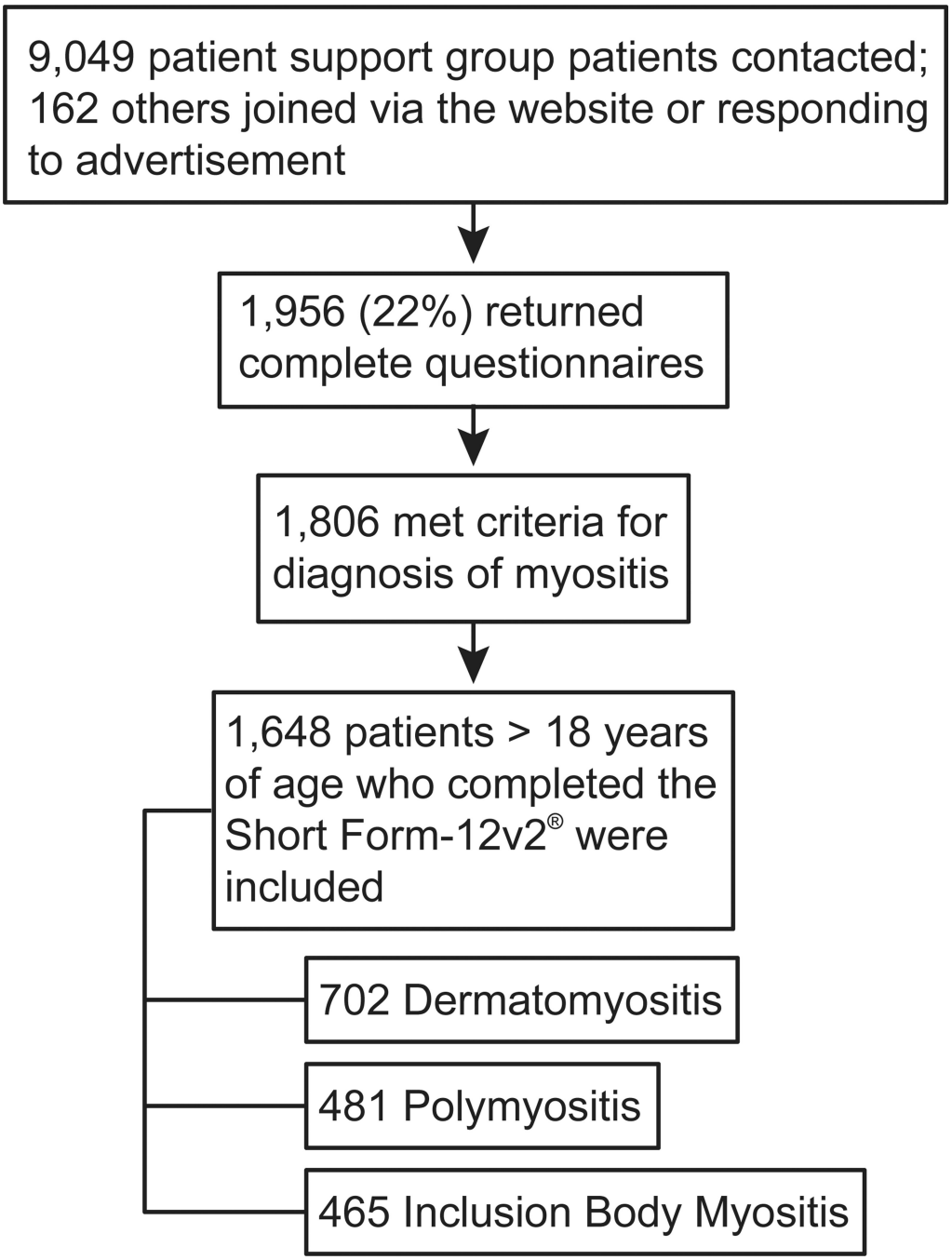


**Figure 1.**
Flow diagram for patient inclusion in the study

**Table 1**

Burden of Disease Relative to an Age- and Gender-Matched United States Sample

| Short Form-12 Domains & Summary scores | Myositis population (N=1,715) | | | General population (N=6,012) | | | Difference between Myositis and General population | |
|---|---|---|---|---|---|---|---|---|
| | Mean | SE | N | Mean | SE | F | P | ES |
| **Physical Functioning** | 33.90 | 0.26 | 6028 | 48.54 | 0.20 | 2000.4 | <*0.0001* | −1.01 |
| **Role Physical** | 35.18 | 0.27 | 6026 | 48.73 | 0.20 | 1618.5 | <*0.0001* | −0.91 |
| **Bodily Pain** | 42.58 | 0.28 | 6007 | 49.43 | 0.21 | 380.6 | <*0.0001* | −0.45 |
| **General Health** | 41.62 | 0.28 | 6024 | 49.21 | 0.21 | 482.1 | <*0.0001* | −0.50 |
| **Vitality** | 42.38 | 0.26 | 5997 | 50.80 | 0.21 | 639.1 | <*0.0001* | −0.55 |
| **Social Functioning** | 40.94 | 0.29 | 6009 | 50.55 | 0.21 | 720.3 | <*0.0001* | −0.62 |
| **Role Emotional** | 42.02 | 0.32 | 6024 | 51.29 | 0.21 | 593.8 | <*0.0001* | −0.59 |
| **Mental Health** | 47.04 | 0.25 | 6026 | 52.24 | 0.21 | 257.2 | <*0.0001* | −0.34 |
| **Physical Summary Score** | 35.56 | 0.26 | 6009 | 47.84 | 0.20 | 1382.7 | <*0.0001* | −0.84 |
| **Mental Summary Score** | 47.26 | 0.27 | 6012 | 52.52 | 0.21 | 241.8 | <*0.0001* | −0.35 |

SE = Standard Error, F = F statistic for ANOVA with sample as a between-subjects, factor P = P-value for F (P-values are in italics when significant), ES = Effect Size (Cohen's *d*). A negative effect size indicates the myositis population has a numerically smaller mean and that the burden of disease is greater than in the general population.

**Table 2**

Burden of Disease Relative to an Age- and Gender-matched United States Rheumatoid Arthritis Sample

| Short Form-12 Domains & Summary scores | Myositis population (N=1,715) | | Rheumatoid Arthritis population (N=463) | | Difference between Myositis and Rheumatoid Arthritis population | | |
|---|---|---|---|---|---|---|---|
| | Mean | SE | Mean | SE | F | P | ES |
| **Physical Functioning** | 33.90 | 0.26 | 41.65 | 0.83 | 79.3 | *<0.0001* | −0.61 |
| **Role Physical** | 35.18 | 0.27 | 42.01 | 0.83 | 61.1 | *<0.0001* | −0.53 |
| **Bodily Pain** | 42.58 | 0.28 | 41.53 | 0.85 | 1.4 | 0.2419 | 0.08 |
| **General Health** | 41.62 | 0.28 | 43.81 | 0.78 | 6.9 | *0.0084* | −0.17 |
| **Vitality** | 42.38 | 0.26 | 46.93 | 0.76 | 32.0 | *<0.0001* | −0.38 |
| **Social Functioning** | 40.94 | 0.29 | 44.44 | 0.87 | 14.7 | *0.0001* | −0.26 |
| **Role Emotional** | 42.02 | 0.32 | 45.18 | 0.94 | 10.2 | *0.0014* | −0.21 |
| **Mental Health** | 47.04 | 0.25 | 48.68 | 0.79 | 3.9 | *0.0478* | −0.14 |
| **Physical Summary Score** | 35.56 | 0.26 | 40.47 | 0.82 | 32.5 | *<0.0001* | −0.39 |
| **Mental Summary Score** | 47.26 | 0.27 | 48.96 | 0.79 | 4.2 | *0.0415* | −0.14 |

SE = Standard Error, F = F statistic for ANOVA with sample as a between-subjects, factor P = P-value for F (P-values are in italics when significant), ES = Effect Size (Cohen's *d*). A negative effect size indicates the myositis population has a numerically smaller mean and that the burden of disease is greater than in the Rheumatoid Arthritis population.

**Table 3**

Multivariate Analysis of the Full MYOVISION Sample for Physical and Mental Component Summary Scores

| Predictors of HRQOL | Physical Component Summary Score (PCS) | | Mental Component Summary Score (MCS) | |
|---|---|---|---|---|
| | Beta Coefficient (standard error) | P | Beta Coefficient (standard error) | P |
| **Polymyositis*** | −4.28 (0.59) | *<0.001* | −1.00 (0.67) | 0.140 |
| **Inclusion Body Myositis*** | −8.94 (0.80) | *<0.001* | −1.10 (0.83) | 0.189 |
| **Female** | −0.09 (0.58) | 0.882 | R | R |
| **Caucasian** | 1.49 (0.80) | 0.063 | 1.08 (0.91) | 0.239 |
| **Age at Enrollment** | −0.08 (0.02) | *<0.001* | 0.02 (0.03) | 0.551 |
| **Disease Duration** | R | R | 0.08 (0.04) | 0.087 |
| **Effect on Work** | −5.43 (0.61) | *<0.001* | −3.52 (0.69) | *<0.001* |
| **Treated by Rheumatologist** | 1.57 (0.59) | *0.008* | R | R |
| **Lung Disease** | −3.48 (0.58) | *<0.001* | −0.80 (0.66) | 0.226 |
| **Dysphagia** | −0.56 (0.50) | 0.263 | −0.96 (0.57) | 0.093 |
| **Joint Swelling** | −2.85 (0.53) | *<0.001* | −2.92 (0.60) | *<0.001* |
| **Received Multiple Immuno-modulators** | −2.61 (0.55) | *<0.001* | −1.00 (0.62) | 0.109 |
| **Cancer Diagnosis** | R | R | 1.53 (0.74) | *0.038* |
| **Autoimmune Overlap** | −1.52 (0.58) | *0.009* | R | R |

R = Removed from analysis by backwards elimination other abbreviations per Table 1

*Polymyositis and Inclusion Body Myositis are each relative to the Dermatomyositis

P-values in italics are significant

**Table 4**

Multivariate Analysis of Myositis Groups for Physical Component Summary Scores (PCS) and Mental Component Summary Scores (MCS)*

| Variable | Dermatomyositis | | Polymyositis | | Inclusion Body Myositis | |
|---|---|---|---|---|---|---|
| | PCS† | MCS† | PCS† | MCS† | PCS† | MCS† |
| **Disease Duration** | R | 0.14 (0.06)<br>*0.024* | R | R | R | 0.14 (0.06)<br>0.233 |
| **Effect on Work** | −7.45 (1.02)<br>*<0.001* | −3.81 (1.00)<br>*<0.001* | −4.60 (1.16)<br>*<0.001* | −4.06 (1.27)<br>*0.001* | −2.82 (0.83)<br>*<0.001* | −2.82 (1.40)<br>*0.044* |
| **Treated by Rheumatologist** | 2.94 (1.03)<br>*0.004* | 2.37 (1.02)<br>*0.02* | R | R | −1.22 (0.81)<br>0.133 | −3.00 (1.33)<br>*0.025* |
| **Lung Disease** | −4.16 (0.93)<br>*<0.001* | −0.98 (0.92)<br>0.285 | −4.02 (1.03)<br>*<0.001* | R | −0.73 (0.92)<br>0.428 | −2.80 (1.57)<br>0.076 |
| **Dysphagia** | −1.68 (0.84)<br>*0.046* | R | R | R | R | −2.30 (1.16)<br>*0.048* |
| **Joint Swelling** | −3.39 (0.84)<br>*<0.001* | −2.76 (0.83)<br>*<0.001* | −1.89 (0.99)<br>0.058 | −4.07 (1.09)<br>*<0.001* | −1.75 (0.80)<br>*0.029* | R |
| **Multiple Immuno-modulators** | −1.82 (0.93)<br>*0.049* | R | −3.24 (0.98)<br>*0.001* | −0.36 (1.08)<br>0.736 | −1.79 (0.82)<br>*0.029* | R |
| **Autoimmune Overlap** | −2.26 (0.90)<br>*0.013* | R | R | R | R | R |

*Only significant variables are shown in the table

†Each column shows – Parameter estimate (Standard error)

P-values are listed on the 2nd line for each variable and are in italics when significant

R = Removed from analysis by backwards elimination